

# Tardive dyskinesia: screening and risk disclosure

Robert Chaplin and Mark Potter

A questionnaire was sent to a random sample of 339 psychiatrists on the Royal College mailing list, enquiring about their practice of screening and risk disclosure in patients at risk of tardive dyskinesia. The response rate was 70%. There was wide variation in the rate of informing patients of the risk. Over half of the respondents felt that knowledge about tardive dyskinesia would reduce compliance, a view which predicted a low rate of informing patients. There was support for the issuing of clinical practice guidelines by the College. Psychiatrists need further education about tardive dyskinesia.

The risk of tardive dyskinesia complicating antipsychotic treatment is well established. Kane *et al* (1984) reported an incidence of 3–4% of patients per year receiving new prescriptions, indicating tardive dyskinesia may complicate relatively short-term treatment. The prevalence is 20% of patients receiving long-term prescriptions (Woerner *et al*, 1991).

In the USA, most states have statutory policies concerning disclosure of risk of antipsychotics. The American Psychiatric Association has issued guidelines for screening practices and methods of obtaining informed consent to treatment and some centres operate local policies for management of tardive dyskinesia. However, a postal questionnaire study found clinicians needed educating about the prevention of tardive dyskinesia (Benjamin & Munetz, 1994). The situation in Britain is very different with neither statutory policies nor clinical guidelines covering disclosure of the risk of tardive dyskinesia. This study investigates the practice of screening and risk disclosure of tardive dyskinesia among British psychiatrists.

## The study

A nine item, self-administered questionnaire was adapted from that developed by Benjamin & Munetz (1994) for use in Britain. The areas covered were the existence of a tardive dyskinesia monitoring policy, the frequency of and staff responsible for screening, personal experience of litigation, the extent to which patients are informed about tardive dyskinesia and views

about formal policies for screening and risk disclosure.

The questionnaire received approval by the Royal College of Psychiatrists' Research Committee, was piloted by psychiatrists locally and sent on three occasions to a random sample of psychiatrists on the College mailing list. These included College members and inceptors, but excluded those belonging to special interest groups in child and adolescent psychiatry, psychotherapy and drug and alcohol use. It was anonymous although the respondents were asked to state their age, gender and regional health authority.

## Findings

Two hundred and thirty-eight (70%) questionnaires were returned and a total of 221 (65%) were filled out correctly. Respondents had a mean age of 42 (range 25–65); 69% were male, and represented all regions of Britain. With regard to speciality, 55% indicated they practised general psychiatry, 22% old age, 12% learning disabilities, 6% forensic and 4% child and adolescent.

They were asked about screening practices for patients at risk of tardive dyskinesia. A regular screening interval was given by 45% of respondents but only 4% stated their service had a formalised screening policy. Medical staff performed the majority of assessments and were aided by community psychiatric nurses in the services of 53% of respondents. Other mental health professionals only rarely took part. The assessment of tardive dyskinesia was most commonly performed by observation of the patient (94% of replies), included a medical examination in only 35% of replies and the use of a structured instrument (e.g. the Abnormal Involuntary Movements Scale; AIMS; Guy, 1976) in 5%.

Litigation had personally been experienced by only one respondent, a further 12% knew of litigation involving other clinicians but the majority (65%) were concerned about possible litigation by patients with tardive dyskinesia. There was support for the development of guidelines by the Royal College of Psychiatrists from 74% of respondents, for local guidelines from 26%, but only 4% supported statutory

regulations for screening, management and risk disclosure of tardive dyskinesia.

The respondents were asked how many patients they warned about the risk of tardive dyskinesia (Table 1). Those who said they informed 25% or less of their patients were more likely to be female psychiatrists ( $P=0.03$ ), or specialising in old age rather than in general psychiatry ( $P=0.004$ ), but no less likely to be concerned about litigation ( $P=0.6$ ). The seniority or geographical location of practice of the psychiatrist was not significantly associated with willingness to inform. They were asked to indicate whether they agreed with the statement 'Disclosure of the risk of tardive dyskinesia is harmful as it causes non-compliance with medication and increased relapse risk.' The 55% who indicated that they agreed were significantly more likely to state a low rate (25% or less) of informing patients of risk ( $P=0.004$ ).

Those respondents who indicated that they did not routinely inform patients of the risk of tardive dyskinesia were asked to state why. Of the 70 who replied, the most frequent reasons were fear of non-compliance (32 responses), inability to give informed consent (8 responses) and discussion occurring with relatives instead (8 responses). More surprising responses cited were the rarity of tardive dyskinesia (10 responses), the decision to treat with antipsychotics was made by another clinician (6 responses), lack of time, forgetfulness, the issue was 'not of importance in the elderly', and 'most patients are not bothered' (one response each).

Seventy-six respondents provided general comments. Common themes were supported for risk disclosure policy guidelines, disclosure of risk to be based on an individual risk-benefit analysis, informed consent to antipsychotic treatment would help compliance, and complaints by junior staff about lack of guidance.

## Comment

Psychiatrists lack agreement in their practises of screening and risk disclosure to patients at risk of

Table 1. Psychiatrists' estimation of the percentage of their patients they inform about the risk of tardive dyskinesia

Percentage of patients informed about the risk of tardive dyskinesia	Responses
All patients at risk	34 (15%)
75% of patients at risk	52 (23%)
50% of patients at risk	24 (11%)
25% of patients at risk	62 (28%)
Never inform patients	20 (9%)
Don't know	29 (13%)
Total	221

developing tardive dyskinesia. They seldom medically examine or assess regularly for the condition and almost never use standardised assessments. Although most respondents were concerned about the risk of litigation, only one respondent had personally experienced it. This is further supported by enquiries to the main medical defence organisations who were unaware of any tardive dyskinesia related litigation. Surprisingly, concern or knowledge about litigation did not result in respondents informing more patients of the risk.

This study shows a reluctance to discuss this disabling condition, the most commonly cited reason being fear of non-compliance with medication and relapse. Common law governs real consent to informal treatment and the Sidaway case (BMJ Legal Correspondent, 1985) upheld the right of doctors to withhold information about side-effects of treatment, also called therapeutic privilege. Hence doctors may choose not to disclose a risk if they believe it would be detrimental to a patient's health and it appears that not informing patients about tardive dyskinesia could be justified by this principle.

There is evidence though that informing patients of the risks of antipsychotic treatment does not reduce compliance or harm their mental health and results in an increased knowledge about their treatment (Kleinman *et al*, 1989). It also results in less reporting of side-effects (Brown *et al*, 1987) possibly due to patients feeling less anxious about them. Additionally, as the principle of informed consent is supported in the Department of Health's 1993 Code of Practice of the Mental Health Act 1983, it appears difficult to justify the withholding of information from patients on grounds of feared non-compliance.

There is a need for psychiatrists to reach agreement about informing patients at risk. This could be achieved by clinical practice guidelines or a consensus statement and would receive support from most respondents. Detection of the condition could be improved by the training of non-medical staff in the assessment of patients (Munetz & Benjamin, 1990). Some psychiatrists continue to hold views about tardive dyskinesia that are not supported by current literature, for example the condition being rare, and are in need of continuing education. More research is needed into the risks and benefits of informing patients about tardive dyskinesia.

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\*Robert Chaplin, and Mark Potter, *Department of Mental Health Sciences, St George's Hospital Medical School, Cranmer Terrace, London SW17 0RE*

\*Correspondence

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